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CAREGIVERS IN MEDICAL LAW AND ETHICS

*Jonathan Herring**

1. INTRODUCTION

Medical law and ethics is dominated by individualism. This is characterised by the clarion claims of many that *I* have the right to make decisions about *my* medical treatment; and that *I* should receive the treatment that is appropriate for *me*.¹ The problem with these questions is that, as Martha Minow pointed out, the question ‘who is the patient?’, goes unasked.²

Unasked because many people think the answer is obvious: it is the person sitting in front of the doctor. One of the purposes of this article is to demonstrate that this is far too simplistic a response.³ In medical law, as often in legal thought, the focus is on the image of an autonomous, competent man who can enforce his rights.⁴ In fact, we cannot separate our interests from those with whom we are in interdependent relationships. A patient’s medical decision will rarely affect only herself but will often have a powerful impact on those who depend on her and upon whom she is dependant. Any treatment provided will assist not only the person in front of the doctor, but the many people that individual has a relationship with. A

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Editor’s Note: Due to the foreign residence of the author, the footnotes of this article do not conform to The Bluebook: A Uniform System of Citation.

1. For a powerful polemic against the emphasis on autonomy see: C. Foster, *Choosing Life, Choosing Death: The Tyranny of Autonomy in Medical Ethics and Law* (Hart, forthcoming).

2. M. Minow, “Who’s the Patient?” (1994) 53 *Maryland Law Review* 1173.

3. I have written about the position of caregivers elsewhere: J. Herring, “Where are the Carers in Health Care Law and Ethics?” (2007) 27 *Legal Studies* 51; J. Herring, “Caring” (2007) *Law and Justice* 43; J. Herring, “The Place of Carers” in M. Freeman (ed.) *Law and Bioethics* (OUP, 2008).

4. I use the male pronoun deliberately because the image of the isolated, rational-driven male patient is the image that dominates much of the writing.

The aim of this article is to illustrate these points by considering the position of caregivers⁵ in medical law and ethics. There, as in many other areas of academic and public life, the work of caregivers has been rendered invisible by the focus on individualistic rights.⁶ The article will start with a brief discussion of the social and legal position of caregivers. It will then outline how an approach based on an ethic of care properly takes account of caring relationships. The article will then consider three issues in particular: the relevance of caregivers in the rationing of health care, the weight given to interests of caregivers in decision-making concerning people who lack capacity, and the role of the right of autonomy in medical law.

2. CAREGIVERS

The precise definition of a “caregiver” raises some complex and interesting problems. To demonstrate these, consider the United Kingdom Government’s definition:

[S]omeone who looks after a friend, relative or neighbour who needs support because of their sickness, age or disability.⁷

This definition would appear to include any parent caring for a child, although it is clear from the Government’s publications that the definition is not intended to cover all parents.⁸ Why the UK Government should not consider all parents to be caregivers raises some interesting questions, but for another day. Another issue is whether professional, paid caregivers should be included in the definition.⁹ More success may be found if we attempt to define caring. Daniel Engster proposed:

5. In England, the word “carer” is normally used to describe a person who in America is normally known as a “caregiver”. This article will use the American terminology.

6. M. Henwood, *Ignored and Invisible* (Carers’ National Association, forthcoming 2008).

7. Her Majesty’s Government, *Introduction to Caring*, http://www.direct.gov.uk/en/CaringForSomeone/CaringAndSupportServices/DG_10016779.

8. E.g., Department of Health, *Caring About Carers* (Department of Health, 2005) (stating that there are 5.7 million carers, yet making no mention of parents other than those of disabled children). The 5.7 million figure would be much higher if it included all parents.

9. L. Lloyd, “Call us Carers: Limitations and Risks in Campaigning for Recognition and Exclusivity” (2006) 26 *Critical Social Policy* 945.

[C]aring may be said to include everything we do directly to help others to meet their basic needs, develop or sustain their basic capabilities, and alleviate or avoid pain or suffering, *in an attentive, responsive and respectful manner*.¹⁰

That definition raises controversial issues of its own. Is the manner of the caregiving essential to its nature? For the purposes of this article, it is not necessary to delve further into the definitional issue, but rather the UK Government's definition will be used, with the understanding that it is not intended to apply to a parent caring for a healthy child, and does not apply to "professional caregivers."¹¹

The primary focus of this article is on the position of caregivers in the context of medical law, but a very brief discussion about caregivers more generally is useful.¹² In the US it has been estimated that there are 44.4 million caregivers, which is about twenty-one percent of the population.¹³ In the UK, using a narrower definition, it has been said there are approximately seven million caregivers, just under ten percent of the population. A leading UK charity claims that at some point in their lives, three in every five people will become a caregiver.¹⁴ All the signs are that on both sides of the Atlantic there will be an increasing need for informal care, given our aging population.

10. D. Engster, "Rethinking Care Theory: The Practice of Caring and the Obligation to Care" (2005) 20 *Hypatia* 50, at 55 (italics in original).

11. I do not mean by distinguishing "professional" and "non-professional" caregivers to suggest that informal caregivers are somehow less skilled at caring. Many informal caregivers have highly developed care skills.

12. For a helpful discussion see M. Murray, "The Networked Family: Reframing The Legal Understanding Of Caregiving and Caregivers" (2008) 94 *Virginia Law Review* 385; P. Laufer-Ukeles, "Selective Recognition of Gender Difference in the Law: Revaluing the Caretaker Role" (2008) 31 *Harvard Journal of Law & Gender* 1; A. Bookman and M. Harrington, "Family Caregivers: A Shadow Workforce in the Geriatric Health Care" (2007) 32 *Journal of Health Politics, Policy and Law* 1005; N. Folbre, *The Invisible Heart: Economics and Family Values* (New Press, 2001); N. Folbre and M. Bittman (eds), *Family Time: The Social Organization of Care* (Routledge, 2004); N. Hooman and J. Gonyea, *Feminist Perspectives on Family Care: Policies for Gender Justice* (Sage, 1995).

13. National Alliance for Caregiving and AARP, *Caregiving in the US* (National Alliance for Caregiving and AARP, 2004), at 6.

14. Carers UK, *Facts About Carers* (Carers UK, 2005), at 1.

Preconceptions about caregivers abound. The assumption that caring is performed by middle aged people for older people is inaccurate. Many caregivers are older people, caring for their ailing partners or family members.¹⁵ In the UK there are 8,000 caregivers over the age of ninety.¹⁶ Caring is a significantly gendered activity.¹⁷ Most care is performed by women, although men appear to be undertaking an increasing amount of care.¹⁸ The burden of care falls primarily on women, and where it does, the economic impact on them is greater.¹⁹ This is particularly so as care for frail parents can come at a time in life when a woman may be seeking to rebuild a career in the labor market, after raising children.²⁰

Despite the joys that caring can bring, care work is associated with significant disadvantages.²¹ Many caregivers in both the US and the UK suffer financial hardship due to the impact of care work on their paid employment²² and, due to the impact on pension provision, this continues

15. Carers UK, *Caring and Pensioner Poverty* (Carers UK, 2008).

16. Carers UK, *Older Carers in the UK* (Carers UK, 2005), at 1.

17. E. Watson and J. Mears, *Women, Work and Care of the Elderly* (Ashgate, 1999); E. Feder Kittay, *Love's Labor: Essays on Women, Equality and Dependency* (Routledge, 1999); J. Parks, *No Place Like Home? Feminist Ethics and Home Health Care* (Indiana University Press, 2003), at 22.

18. In a US survey it was found that thirty-nine percent of caregivers were men. National Alliance for Caregiving and AARP, *Caregiving in the US* (National Alliance for Caregiving and AARP, 2004), at 8.

19. J. Parks, *No Place Like Home? Feminist Ethics and Home Health Care* (Indiana University Press, 2003).

20. P. Bywaters and A. Harris, "Supporting Carers: Is Practice Still Sexist?" (1998) 6 *Health and Social Care in the Community* 458.

21. M. Hirst, "Carer Distress: A Prospective, Population-Based Study" (2005) 61 *Social Science & Medicine* 697.

22. As an increasing number of women are employed, this cost is increasing. National Alliance for Caregiving and AARP, *Caregiving in the US* (National Alliance for Caregiving and AARP, 2004) 56-61; F. Carmichael and S. Charles, "The Opportunity Costs of Informal Care: Does Gender Matter?" (2003) 22 *Journal of Health Economics* 781.

into retirement.²³ Older caregivers are particularly vulnerable.²⁴ Care work can have a negative impact on caregivers' health,²⁵ both physical²⁶ and emotional.²⁷ In one UK survey nine out of ten caregivers reported suffering stress, anxiety, depression or loss of sleep.²⁸ These pressures may be particularly strong on what some sociologists have called the "sandwich generation," where women care for both their children and their parents simultaneously. It has been claimed that a third of women in the UK are giving care to both generations.²⁹ Of course, it would be quite wrong to paint a picture of caring being all doom and gloom. There are many aspects of caregiving which people find valuable and worthwhile.³⁰

Caregiving and AARP, 2004) 56-61; F. Carmichael and S. Charles, "The Opportunity Costs of Informal Care: Does Gender Matter?" (2003) 22 *Journal of Health Economics* 781.

23. Carers UK, *Carers UK Welcomes White Paper* (Carers UK, 2006).

24. Carers UK, *Older Carers in the UK* (Carers UK, 2008).

25. Department of Health, UK, *Carers at the Heart of 21st Century Families and Communities: A Caring System on your Side, a Life of your Own* (Department of Health, 2008).

26. M. Hirst, *Hearts and Minds: The Health Effects of Caring* (Carers UK, 2004).

27. M. Hirst, "Carer Distress: A Prospective, Population-Based Study" (2005) 61 *Social Science & Medicine* 697.

28. B. Keeley and M. Clarke, *Carers Speak Out Project* (Princess Royal Trust for Carers, 2002). See also G. Deimling et al, "Care-related Stress. A Comparison of Spouse and Adult-Child Caregivers in Shared and Separate Households" (1989) 1 *Journal of Aging and Health* 67.

29. E. Grundy and J. Henretta, "Between Elderly Parents and Adult Children: A New Look at the Intergenerational Care Provided by the 'Sandwich Generation'" (2006) 26 *Ageing & Society* 707.

30. H. Al-Janabi, J. Coast and T. Flynn, "What Do People Value when they Provide Unpaid Care for an Older Person? A Meta-Ethnography with Interview Follow-up" (2008) 67 *Social Science and Medicine* 111.

Until recently, care work has gone largely unacknowledged by lawyers and politicians.³¹ It was seen as a private matter of little public significance. Few would say that today. The importance of the work performed by informal caregivers is receiving increasing public attention. Without it, the burden on the state of caring for those unable to care for themselves would be enormous.³² The economic value of caregiving is valued at 257 billion dollars annually in one 2002 estimate for the US,³³ and 87 billion pounds in the UK as of 2007.³⁴ Not surprisingly, therefore, many Western Governments are paying a great deal of interest to caregivers.³⁵ A President's Council on Bioethics report states:

There is no question that we are on the threshold of a "mass geriatric society," a society of more long-lived individuals than ever before in human history. For this great gift of longer and healthier life for ourselves and our loved ones we are, and should be, enormously grateful....At the same time, however, there are good reasons to be concerned about the human and moral shape that a mass geriatric society will take, especially if the "price" many people pay for the gift of added years of healthier life is a period of protracted debility, dementia, and dependence stacked up at the end before they eventually die. Such a reshaping of the lifecycle will create enormous challenges for nearly every family and for the entire society. The economic challenges facing Social Security, Medicare, and Medicaid are more or less well known. A looming crisis of long-term care for the incapacitated has received less attention, partly because we prefer

31. This has been accepted by the UK Government. Department of Health, UK, *Carers at the Heart of 21st Century Families and Communities: A Caring System on your Side, a Life of your Own* 8 (Department of Health, 2008).

32. H. Arksey, "Combining Work and Care: The Reality of Policy Tensions for Carers" (2007) 15 *Benefits* 139.

33. P. Arno, *Economic Value of Informal Caregiving*: paper presented at the Annual Meeting of the American Association of Geriatric Psychiatry, Orlando, FL, February 24, 2002, cited in National Alliance for Caregiving and AARP, *Caregiving in the US* (National Alliance for Caregiving, 2004), at 3.

34. Carers UK, *Carers Save UK £85 Billion per Year* (Carers UK, 2007).

35. The Princess Royal Trust for Carers, *Eight Hours a Day and Taken for Granted* (PRTC, 1998); P. Smith, "Elder Care, Gender, and Work: The Work-Family Issue of the 21st Century" (2004) 25 *Berkeley Journal of Employment and Labour Law* 351.

to avert our gaze, largely because we lack an adequate human and ethical understanding of this issue.³⁶

Not only governments are worried. We all care very much about how we will be looked after in our old age. One international study of middle-aged people found considerable anxiety about care in later life.³⁷ It also showed how attitudes about how we expect to be looked after are changing. The authors commented:

One of the most striking and consistent findings from the focus groups was a broad agreement that one's children would be unlikely to be one's main or sole carers.... Relatively few people wanted to receive a major part of their care in old age from their children or other younger members of their family.... Participants across the focus groups for all cultures reported that they had grown up with an expectation that they would care for their parents but did not think that their children had that expectation.³⁸

Not surprisingly, the survey found a strong dislike of the idea of residential care, with its perceived loss of independence and concerns over the quality of care offered. How the desire for independence and informal care can be reconciled with the desire not to burden children remains to be seen. As this survey indicates, our attitudes towards care are complex and may be undergoing change. The UK Government acknowledged this:

[F]amily life has changed over the last 50 or so years. The move to smaller nuclear families means that it is no longer as easy to share the caring role as widely as in the past. Society is more mobile and families are more geographically dispersed. More families rely on two incomes, or longer working hours, to maintain an adequate standard of living. Many families find it difficult to balance work with the care needs of friends and relatives without significantly impacting on their own standard of living, esteem and independence – the lifestyle to which the family has become accustomed.³⁹

36. President's Council on Bioethics, *Taking Care* (President's Council on Bioethics, 2005), at xvii-xviii.

37. R. Levenson, M. Jeyasingham and N. Joule, *Looking Forward to Care in Old Age Expectations of the Next Generation* (Kings Fund, 2005).

38. Ibid. at 29-30.

39. Department of Health, UK, *Carers at the Heart of 21st Century Families and Communities: A Caring System on your Side, A Life of your Own* (Department of Health, 2008), at para. 1.61.

These comments are equally true in the US context.

The nature of care for older people has certainly changed. Robert Goodin and Diane Gibson⁴⁰ have written of the “decasualization” of care of older people. In the past, they suggest, care of older people was casual. Not in the sense of being unloving or unthoughtful, but rather that it was simply integrated into everyday life. A person would not see themselves as specifically spending some time “caring” or undertaking a “care task.” They see the increased professionalisation of care, the increased number of people requiring care, and the diverse pressures facing caregivers as putting strain on the kind of care offered. Whether, as the study just referred to indicates, we are moving to a time when care will predominantly be carried out by professional caregivers remains to be seen. We certainly seem to be seeing a relocation of care from private to the public, and from collective services to commercial ones.⁴¹

As already mentioned, care-work has until recently largely been ignored in political and academic writings. Susan Dodds complained that people who provide care are undervalued, exploited, and expected to meet unrealistic standards.⁴² In the political sphere, it has been forcefully argued that society has gained enormously from the unrecognized, unrewarded carework, mainly undertaken by women. As already mentioned, the economic value of this care work is considerable. Martha Fineman wrote:

[D]ependency is universal and inevitable – the experience of everyone in society and, for that reason, of collective concern, requiring collective response. However, the essential and society-preserving work inevitable dependency demands has been channeled by society in such a way as to make only *some* of its members bear the burdens of this work. As a result, I argue that there is a societal debt owed to caretakers.... The existence of this debt must be recognized, and payment accomplished, through policies and laws that provide both some economic compensation and structural accommodation to caretakers.⁴³

40. R. Goodwin and D. Gibson “The Decasualisation of Eldercare” in E. Feder Kittay and E. Feder (eds), *The Subject of Care: Feminist Perspectives on Dependency* (Rowman & Littlefield, 2003), at 247.

41. S. Sevenhuijsen, “The Place of Care, The Relevance of the Feminist Ethic of Care for Social Policy” (2003) 4 *Feminist Theory* 179, 181.

42. S. Dodds, “Depending On Care: Recognition of Vulnerability and the Social Contribution of Care Provision” (2007) 21 *Bioethics* 500, 502.

43. M. Fineman, *The Autonomy Myth* (New Press, 2004), at 263.

She goes on to argue:

The theory of dependency I set forth develops a claim of “right” or entitlement to support and accommodation from the state and its institutions on the part of caretakers – those who care for dependents. Their labor should be treated as equally productive even if unwaged, and should be measured by its societal value, not by economic or market indicators. The fact that dependency work has been un- or undervalued in the market is an argument *for* governmental intervention and restructuring to mandate adjustment and market accommodation, as well as more direct reparations.⁴⁴

To many feminist commentators, the failure to recognize and value carework has played an important part in disadvantaging women.

In 2008, the UK Government produced a paper entitled *Carers at the Heart of 21st-Century Families and Communities*, which was a major re-examination of the relationship between caregivers and the state. In its introduction, Gordon Brown, the Prime Minister of the United Kingdom, declared:

Caring for our relatives and friends when they are in need is a challenge that the vast majority of us will rise to at some point in our lives. At any one time 1 in 10 people in Britain is a carer – the majority of them, of course, still women. It is a testimony to the importance of families that so many of us are prepared to make the personal sacrifices that caring can involve in order to help our loved ones lead fulfilling lives even in the face of incapacity or disability. Our support and appreciation for carers is therefore not just fundamental to ensuring that those of us in need of care are able to receive it, but goes right to the heart of our values as a society and our ambition to create a fairer Britain.⁴⁵

As this indicates, there is increasing public recognition, politically, of the role caregivers play, but this has not yet fed through to medical law.

Before moving on, it must be emphasised that it is easy to place together “caregivers” as a homogenous category, whereas, of course, they are not. The needs and interests of frail spouses looking after each other may be very different from a neighbour who gives daily help to a friend, or a child

44. Ibid, at xv.

45. Department of Health, UK, *Carers at the Heart of 21st Century Families and Communities: A Caring System on your Side, A Life of your Own* (Department of Health, 2008), at 2. See also F. Carmichael, G. Connell, C. Hulme, and S. Sheppard, *Meeting the Needs of Carers: Government Policy and Social Support* (University of Salford, 2005).

looking after a parent. Further, there may be particular issues facing caregivers on the grounds of their race⁴⁶ or sexual orientation.⁴⁷

3. LAW AND INDIVIDUALISM

The legal and social response to caring provides a challenge to the way legal rights and responsibilities are understood.⁴⁸ Much of the law is based on the assumption that we are competent, detached, independent people who are entitled to have our rights of self-determination and autonomy fiercely protected.⁴⁹ However, the reality is that we are ignorant, vulnerable, interdependent individuals, whose strength and reality is not in our autonomy, but our relationships with others.⁵⁰

Rather than the focus of the law being on individuals, it should be based on a norm of interlocking mutually dependent relationships. Many of those sympathetic to such a claim have turned to ethics of care as an alternative to traditional rights-based approaches.⁵¹ This promotes a vision of people with interdependent relationships as the norm around which legal and ethical responses should be built. The values that are promoted within an ethic of care are not isolated autonomy or the pursuance of individualized rights, but

46. Carers UK, *Black and Minority Ethnic Carers* (Carers UK, 1998); J. Kosberg, A. Kaufman, L. Burgio, J. Leeper, and F. Sun, "Family Caregiving to those with Dementia in Alabama" (2007) 19 *Journal of Aging and Health* 3.

47. J. Manthorpe and E. Price, "Lesbian Carers: Personal Issues and Policy Responses" (2005) 5 *Social Policy & Society* 15.

48. R. Tong, "The Ethics of Care: A Feminist Virtue Ethics of Care for Healthcare Practitioners" (1998) 23 *Journal of Medicine and Philosophy* 131.

49. L. Lloyd, "Mortality and Morality: Ageing and the Ethics of Care" (2004) 24 *Ageing and Society* 235.

50. C. Meyers, "Cruel Choices: Autonomy and Critical Care Decision-Making" (2004) 18 *Bioethics* 104; J. Tronto, *Moral Boundaries* (Routledge, 1993), at 167-70.

51. E.g., C. Gilligan, "Moral Orientation and Moral Development" in E. Kittay and D. Meyers (eds.), *Women and Moral Theory* (Rowman and Littlefield, 1987); M. Friedman, *Liberating Care* (Cornell University Press, 1993); S. Sevenhuijsen, *Citizenship and The Ethics of Care* (Routledge, 1998); R. Groenhout, *Connected Lives: Human Nature and an Ethics of Care* (Rowman and Littlefield, 2004); V. Held, *The Ethics of Care* (Oxford University Press, 2006); D. Engster, *The Heart of Justice: Care Ethics and Political Theory* (Oxford University Press, 2007).

1. Dependency and care are an inevitable part of being human.⁵² Caring relationships are what life is all about.⁵³ Although the extent of caring may vary, there is probably no point in our lives at which we are neither cared for nor are caring for another. As Jo Bridgeman recently emphasised, it is wrong to assume that the only kinds of dependencies are those between parents and children, or between caregivers and those with disabilities. Even a single person with no ailing relative to care for will be dependant on friends or others in a host of ways.⁵⁴ In failing to properly acknowledge care work, the law misses an important and inevitable aspect of life. Eva Feder Kittay wrote of our interdependence:

My point is that this interdependence begins with dependence. It begins with the dependency of an infant, and often ends with the dependency of a very ill or frail person close to dying. The infant may develop into a person who can reciprocate, an individual upon whom another can be dependent and whose continuing needs make her interdependent with others. The frail elderly person . . . may herself have been involved in a series of interdependent relations. But at some point there is a dependency that is not yet or no longer an interdependency. By excluding *this* dependency from social and political concerns, we have been able to fashion the pretense that we are *independent* – that the cooperation between persons that some insist is *interdependence* is simply the mutual (often voluntary) cooperation between essentially independent persons.⁵⁵

Often in legal academy, caregiving is ignored or hived off to a special corner of its own, such as at the borderland of family law. However, as Joan Tronto wrote:

Care is not a parochial concern of women, a type of secondary moral question, or the work of the least well off in society. Care is a central

52. M. Fineman, *The Autonomy Myth* (New Press, 2004), at xvii; T. Levy, “The Relational Self and the Right to Give Care” (2006) 28 *New Political Science* 547, at 548.

53. F. Williams, “The Presence of Feminism in the Future of Welfare” (2002) 31 *Economy and Society* 502, at 509.

54. J. Bridgeman, “Book Review” (2006) 14 *Feminist Legal Studies* 407, at 408. See also J. Herring and P.-L. Chau, “My Body, Your Body, Our Bodies” (2007) 15 *Medical Law Review* 34, at 51.

55. E. Feder Kittay, *Love’s Labor: Essays on Women, Equality and Dependency* (Routledge, 1999), at xii (emphasis in original).

concern of human life. It is time we began to change our political and social institutions to reflect this truth.⁵⁶

2. Not only is care an inevitable part of life; it is a good part of life. Care should be treasured and valued. As Robin West put it:

Caregiving labor (and its fruits) is the central adventure of a lifetime; it is what gives life its point, provides it with meaning, and returns to those who give it some measure of security and emotional sustenance. For even more of us, whether or not we like it and regardless of how we regard it, caregiving labor, for children and the aged, is the work we will do that creates the relationships, families, and communities within which our lives are made pleasurable and connected to something larger than ourselves.⁵⁷

The value of care is not, of course, simply for the individuals themselves. Without caring relationships the burden that would fall onto society would be impossible to bear.⁵⁸ As already mentioned, Martha Fineman⁵⁹ has argued that for too long society has benefited from caring without giving the activity its due value and support. She calls for a reworking of legal and social attitudes so that caring can become recognised as an activity of central significance.⁶⁰

3. Much of medical law emphasises the importance of rationality and intellect. The concepts of mental capacity, informed consent, and compliance with standards expected by a responsible body of opinion, are all privilege in legal discourse logical thought and sound judgement. There is nothing wrong in that, but the emotional side of health is lost. The love that goes on caring; the grief, disappointment, frustration, anger, and despair find no place. Occasionally it peeps through into the legal setting. One example

56. J. Tronto, *Moral Boundaries: A Political Argument for an Ethic of Care*. (Routledge, 1993), at 180.

57. R. West, "The Right to Care" in E. Kittay and E. Feder (eds), *The Subject of Care: Feminist Perspectives on Dependency* (Rowman & Littlefield, 2002), at 89.

58. L. McClain, "Care as a Public Value: Linking Responsibility, Resources, and Republicanism" (2001) 76 *Chicago-Kent Law Review* 1673; M. Daly, "Care as a Good for Social Policy" (2002) 31 *Journal of Social Policy* 251.

59. M. Fineman, *The Autonomy Myth* (New Press, 2004).

60. Ibid. See also, e.g., T. Levy, "The Relational Self and the Right to Give Care" (2007) 28 *New Political Science*, 547.

is the English case of *Re B (Adult: Refusal of Medical Treatment)*⁶¹ where the medical team, who had done so much work to improve the quality of life of the patient and had grown close to her, felt unable to switch off her life support machine as she requested, and as the court ultimately ordered.⁶² In cases involving disputes over the medical treatment of children, judges often contrast the “understandably emotional” views of parents, with the “expert views” of the medical team.⁶³ The exclusion of emotion means the voice of caregivers talking about how their cared-for ones should be looked after finds no ready legal mouthpiece. An ethic of care seeks to acknowledge the role that emotion and rationality plays in relationships. We do not live by rational thoughts alone.⁶⁴

4. In relationships of caring and dependency our interests become intermingled.⁶⁵ We do not break down into ‘me’ and ‘you.’ To harm a caregiver is to harm the person cared-for; to harm the person-cared for is to harm the caregiver. There should be no talk of balancing the interests of the caregiver and the person cared-for, the question rather should be emphasising the responsibilities they owe to each other in the context of a mutually supporting relationship.⁶⁶

Indeed, it is simplistic to imagine we can identify in a caring relationship who is the caregiver and who is the cared-for; their relationship is marked by interdependency. The cared-for provides the caregiver with gratitude, love, acknowledgement and emotional support, which will be of great emotional value to him. Indeed, often a caregiver will be the cared-for in another

61. [2002] All ER 449.

62. She had to be transferred to another hospital so the court order could be effected. V. English, *Withholding and Withdrawing Life-prolonging Medical Treatment: Guidance for Decision Making* (Blackwell, 2007), at 45.

63. M. Brazier, “An Intractable Dispute: When Parents and Professionals Disagree” (2005) 13 *Medical Law Review* 412.

64. For further discussion of this see J. Herring, “Entering the Fog: On the Borderlines of Mental Capacity” (forthcoming 2008) 83 *Indiana Law Journal*.

65. T. Shakespeare, *Help* (Venture, 2000) and T. Shakespeare, “The Social Relations of Care” in G. Lewis, S. Gewirtz and J. Clarke (eds), *Rethinking Social Policy* (Sage, 2001), at 53.

66. G. Clement, *Care, Autonomy and Justice: Feminism and the Ethic of Care* (Westview, 1996), at 11; V. Held, *The Ethics of Care* (Oxford University Press, 2006), chapter 1.

relationship. As Diane Gibson noted, our society is made up of overlapping networks of dependency.⁶⁷

Clare Ungerson convincingly argued that it is wrong to see the relationship between caregiver and cared-for as one where the caregiver has power over the cared-for.⁶⁸ The cared-for might have a range of powers they can exercise.⁶⁹ The emotional well-being of the caregiver can depend on the attitude and response of the cared-for person to the caregiver.⁷⁰ The cared-for has the power to make the life of the caregiver unbearable.

This is not to deny the existence of a self. Eva Feder Kittay argued that one must always “construe oneself and other as selves that are *always* selves-in-relationship.”⁷¹ But as she recognised, there is a difficulty in balancing the need to retain the worth of individuals, with the values of relationships. She argued:

Total self-sacrifice, the annihilation of the self in favor of the cared for, is neither demanded by the practice of care nor is it justifiable, for one can see that a relationship requires *two* selves, not one self in which the other is subsumed and consumed. A care ethic is not a mere reaction to individualism, but it tempers individualism by insisting that the relationships in which we stand help to constitute the individual we have become, are now and will be in the future.⁷²

So a self can only be understood and examined as it exists in its relational context. It is with this in mind that her reference to understanding people as “selves in relationships” is particularly valuable. As Elizabeth Frazer and Nicola Lacey argued:

67. D. Gibson, *Aged Care: Old Policies, New Solutions* (Cambridge University Press, 2005), at 185.

68. C. Ungerson, “Social Politics and the Commodification of Care” (1997) 4 *Social Policy* 362.

69. K. Pillemer and D. Finkelhor, “Causes of Elder Abuse: Caregiver Stress versus Problem Relatives” (2006) 19 *Journal of Health and Human Services Administration* 245.

70. S. Chattoo and W. Ahmad, “The Moral Economy of Selfhood and Caring: Negotiating Boundaries of Personal Care as Embodied Moral Practice” (2008) 30 *Sociology of Health & Illness* 550.

71. E. Feder Kittay, “Searching For An Overlapping Consensus: A Secular Care Ethics Feminist Responds To Religious Feminists” (2007) 4 *University of Saint Thomas Law Journal* 468, at 475.

72. *Ibid.* at 478.

The notion of the relational self, in contrast to both atomistic and inter-subjective selves, nicely captures our empirical and logical interdependence and the centrality to our identity of our relations with others and with practices and institutions, whilst retaining an idea of human uniqueness and discreteness as central to our sense of ourselves. It entails the collapse of any self/other or individual/community *dichotomy* without abandoning the idea of genuine agency and subjectivity.⁷³

5. An ethic of care emphasises the importance of responsibilities within caring relationships.⁷⁴ Supporters of an ethic of care argue that the focus of the enquiry should be what is my proper obligation within the context of this relationship, rather than it being is it my right to do X.⁷⁵ Virginia Held made this point by contrasting an ethic of care and an ethic of justice:

An ethic of justice focuses on questions of fairness, equality, individual rights, abstract principles, and the consistent application of them. An ethic of care focuses on attentiveness, trust, responsiveness to need, narrative nuance, and cultivating caring relations. Whereas an ethic of justice seeks a fair solution between competing individual interests and rights, an ethic of care sees the interest of carers and cared-for as importantly intertwined rather than as simply competing.⁷⁶

It should be added that Held makes it clear that an ethic of care includes justice: “[t]here can be care without justice: There has historically been little justice in the family, but care and life have gone on without it. There can be no justice without care, however, for without care no child would survive and there would be no persons to respect.”⁷⁷ It is easy in a discussion of an ethic of care to glamorize care. No one should overlook the sheer exhaustion and exasperation that caring brings.⁷⁸ Caring can be mucky,

73. E. Frazer and L. Lacey, *The Politics of Community: A Feminist Critique of the Liberal-Communitarian Debate* (Harvester Wheatsheaf, 1993), at 178.

74. See generally J. Bridgeman, *Parental Responsibility, Young Children and Healthcare Law* (Cambridge University Press, 2008), chapter 1.

75. V. Held, *The Ethics of Care* (Oxford University Press, 2006), at 15.

76. *Ibid.* at 15.

77. *Ibid.* at 17.

78. See generally M. Goldsteen, T. Abma and B. Oeseburg, “What is it to be a Daughter? Identities Under Pressure in Dementia Care” (2007) 21 *Bioethics* 1.

nasty, and frustrating.⁷⁹ Care is hard work; extremely hard work.⁸⁰ Caregivers can often feel trapped: their life goals come to an end and they must adopt the role of caregiver while the rest of their life is put on hold.⁸¹ In his book, *The Selfish Pig's Guide to Caring*, Hugh Marriott, clearly a devoted caregiver himself, had this to say:

We didn't apply for the job. Most of us don't have a vocation for it. We've had no training. We're certain we aren't much good at it. Plus, and this is the nub of the matter, we've got our own life to lead. Are we expected to throw that away because of somebody else's disability? We've got things to do, places to go. And now it looks as if we might not be able to.

But aren't we just as important as they are? Why are we expected to sacrifice ourselves for somebody else? And yes, I mean sacrifice. We're not talking about giving up five minutes of time once or twice a week. Or putting off a holiday from this year to next. We're talking about changing our entire way of life. The old one wasn't perfect, but it was the best we could do. This new one isn't even ours. It's somebody else's life. And it's one that doesn't suit us at all.⁸²

Caring can become abusive for both the caregiver and cared-for. As Robin West put it, "[r]elationships of care, untempered by the demands of justice, resulting in the creation of injured, harmed, exhausted, compromised, and self-loathing 'giving selves,' rather than in genuinely compassionate and giving individuals, are ubiquitous in this society."⁸³ But this is why it is so important that those sympathetic to an ethic of care emphasise the importance of upholding justice and responsibility within relationships.⁸⁴ An ethic of care that promotes mutual obligation and

79. See generally K. Abrams, "The Second Coming of Care" (2001) 76 *Chicago-Kent Law Review* 1605; J. Oliver and A. Briggs, *Caring Experiences of Looking After Disabled Relatives* (Routledge, 1985).

80. See generally A. Hubbard, "The Myth of Independence and the Major Life Activity of Caring" (2004) 8 *Journal of Gender, Race and Justice* 327; C. Ungerson, "Social Politics and the Commodification of Care" (1997) 4 *Social Policy* 362.

81. Department of Health, *Caring about Carers* (London: Department of Health, 1999), at 12.

82. H. Marriott, *The Selfish Pig's Guide to Caring* (Polperro, 2003), at 9.

83. R. West, *Caring for Justice* (New York University Press, 1997), at 81.

84. J. Kroeger-Mappes, "The Ethic of Care Vis-a-Vis the Ethic of Rights: A Problem for Contemporary Moral Theory" (1994) 9 *Hypatia* 108, at 110.

support within a relationship should never be used to permit abuse to develop. Indeed, a relationship-based approach can be more alert than any other to the dangers of misuse of a relationship.⁸⁵

One of the most powerful criticisms of an ethic of care is that care relationships, despite their cozy sounding image, are in fact about power. John Eekelaar wrote:

...[T]o exercise care is also to exercise power. True, it is to be hoped that it is a beneficent exercise of power, but it is power nonetheless. The key element, overlooked in some communitarian accounts, is the role of force or coercion. There are many examples where the role of caregiver, even if applied with good intentions, has adverse consequences.⁸⁶

As mentioned earlier, it is a mistake to assume that the caregiver exercises power over the person cared for. Caring relations often involve a complex interplay of dependencies and vulnerabilities.⁸⁷ As Michael Fine and Caroline Glendinning argued:

Recent studies of care suggest that qualities of reciprocal dependence underlie much of what is termed “care”. Rather than being a unidirectional activity in which an active care-giver does something to a passive and dependent recipient, these accounts suggest that care is best understood as the product or outcome of the relationship between two or more people.⁸⁸

Eekelaar is correct to be concerned about the power that can undoubtedly be exerted in a caring relationship. However, that is not an automatic consequence of caring and it reminds us how important it is to emphasize the elements of justice and responsibility within an ethic of care.

85. See M. Chen-Wishart, “Undue Influence: Vindicating Relationships of Influence” in J. Holder and C. O’Cinneide (eds), *Current Legal Problems* (Oxford University Press, 2007).

86. J. Eekelaar, *Family Law and Personal Life* (Oxford University Press, 2007), at 178-79. See also R. Wood, “Care of Disabled People” in G. Dalley (ed.) *Disability and Social Policy* (Policy Studies Institute, 1991).

87. C. Chorn and J. Harms Cannon, “‘They’re Still in Control Enough to be in Control’: Paradox of Power in Dementia Caregiving” (2008) 22 *Journal of Aging Studies* 45.

88. M. Fine and C. Glendinning, “Dependence, Independence or Inter-Dependence? Revisiting the Concepts of Care and Dependency” (2005) 25 *Ageing and Society* 601, at 616.

4. PUTTING AN ETHIC OF CARE INTO PRACTICE

Under an ethic of care, the practice of caring would be highly valued within society. Caregivers would, far from being hidden, come to represent a norm. Social structures and attitudes would need to be set up to encourage and enable caring. This would require adequate remuneration of caregivers: not the payment of benefits of the kind paid to those “unable to work,” but payment acknowledging the key role they play.⁸⁹ Work would need to be done to ensure that the burden of caring did not fall on the few but was shared across the community.

Susan Dodds argued that we need a legal and social system which is not premised on individualistic conceptions of autonomy but an acceptance of our vulnerability:

A vulnerability-centered view of the self and of persons is better able to capture many of our moral motivations and intuitions than can be captured by an autonomy-focused approach. We are all vulnerable to the exigencies of our embodied, social and relational existence and, in recognizing this inherent human vulnerability, we can see the ways in which a range of social institutions and structures protect us against some vulnerabilities, while others expose us to risk. We do not have to view our obligations towards those who lack the capacity to develop or retain autonomy as having a different source from our obligations towards those whose autonomy is made vulnerable due to a degree of dependency. It may be easier to recognize the social value of provision of care if it is viewed as something on which we all have been dependent and on which we are all likely to be dependent at different points in our lives, rather than altruistic behaviour extended to those who lack “full personhood.”⁹⁰

When assessing the rights of any individual or the medical needs of an individual, such a person would have to be considered in a situational context. Never should it be a matter of assessing a person in isolation. Rather each person’s needs and rights must be considered in the context of their relationships.

There are a host of practical implications that adopting an ethic of care would have when considering the position of caregivers in medical law. I

89. The payment of carers has been said to carry dangers of causing the “marketisation of intimacy and the commodification of care.” C. Ungerson, “Cash in Care” in M Harrington Meyer (ed), *Care Work: Gender Class and the Welfare State* (Routledge, 2000), at 69.

90. S. Dodds, “Depending On Care: Recognition of Vulnerability and the Social Contribution of Care Provision” (2007) 21 *Bioethics* 500, at 507.

will consider three next. There are plenty of others that could be considered. Space does not permit a proper consideration of whether caregivers work should be paid for, and if so, how;⁹¹ whether caregivers should be entitled to compensation from the estate of the dependants;⁹² whether caregivers should be regarded as a group entitled to protection under discrimination law;⁹³ to what extent caregivers should have rights under employment law;⁹⁴ whether social and medical services should be targeted at caregivers or those in need of care;⁹⁵ how an ethic of care can be applied in a clinical setting;⁹⁶ whether the practice of medicine has become too commodified and, based on technology, losing its roots in caring;⁹⁷ or how to deal with the work/care/life balance that is a daily struggle for many.⁹⁸

91. See generally S. Himmelweit, "The Prospects for Caring: Economic Theory and Policy Analysis" (2007) 31 *Canadian Journal of Economics* 581; C. Ungerson and S. Yeandle, *Cash for Care in Developed Welfare States* (Palgrave, 2007).

92. See generally J. Herring "Together Forever? The Rights and Responsibilities of Adult Children and their Parents" in J. Bridgeman, H. Keating, and C. Lind, *Responsibility, Law and the Family* (Ashgate, 2008).

93. See generally J. Williams and S. Bornstein, "Caregivers in the Courtroom: the Growing Trend of Family Responsibilities Discrimination" (2006) 41 *University of San Francisco Law Review* 171.

94. See generally J. Williams and N. Segal, "Beyond the Maternal Wall: Relief for Family Caregivers who are Discriminated Against on the Job" (2003) 26 *Harvard Women's Law Journal* 77.

95. See generally H. Arksey and C. Glendinning, "Choice in the Context of Informal Care-Giving" (2007) 15 *Health and Social Care in the Community* 165.

96. See generally P. Bowden, "An 'Ethic of Care' in Clinical Settings: Encompassing 'Feminine' and 'Feminist' Perspectives" (2000) 1 *Nursing Philosophy* 36.

97. See generally J. Lumby, *Who Cares? The Changing Health Care System* (Allen & Unwin, 2001).

98. See generally C. Williams, *Unbending Gender: Why Family and Work Conflict and What to Do About It* (Oxford University Press, 2001); and D. Kaminer, "The Work-Family Conflict: Developing a Model of Parental Accommodation in the Workplace" (2004) 54 *American University Law Review* 305.

5. CAREGIVERS AND RATIONING MEDICAL RESOURCES

There is now general acceptance that rationing has become a routine part of the provision of health care services in both the United States and United Kingdom. In George P. Smith II's magisterial work, *Distributive Justice and the New Medicine*,⁹⁹ he boldly states that the rationing of health care resources in the US has been "in effect for quite some time."¹⁰⁰ In England rationing decisions are made quite openly with the National Institute for Health and Clinical Excellence (NICE¹⁰¹) determining which medicines are, or are not, to be made available on the National Health Service. The rationing of medical treatment is not only a controversial and complex topic, but also one of great societal importance.¹⁰² As Smith explained:

Essentially, all efforts to achieve justice in the distribution of health care resources are utilitarian in character and definition. Since these resources are not infinite, they cannot be offered to or used by everyone. This, of necessity, then forces choices between those individuals and among groups seeking their use. Allowing improper distribution of these scarce resources is not only inefficient, it is wasteful.¹⁰³

Not surprisingly, attempts have been made to produce a formula that will ensure that decisions are made which take on board, in an appropriate way, the benefits and costs of different treatments and enable them to be compared. Additionally, such formulas are perhaps the smallest of fig leaves to hide behind in the face of a patient being denied treatment.¹⁰⁴

99. George P. Smith II, *Distributive Justice and the New Medicine* (Edward Elgar, 2008).

100. Ibid. at 25. See also M. Kapp, "De Facto Health-Care Rationing by Age" (1998) 19 *Journal of Legal Medicine* 323.

101. To critics this acronym holds a degree of irony. J. Harris, "It's Not NICE to Discriminate" (2005) 31 *Journal of Medical Ethics* 373.

102. J. King, "The Justiciability of Resource Allocation" (2007) 70 *Modern Law Review* 197; K. Syrett, "Nice Work? Rationing, Review and the 'Legitimacy Problem' in the New NHS" (2002) 10 *Medical Law Review* 1.

103. George P. Smith II, *Distributive Justice and the New Medicine* (Edward Elgar, 2008), at 1.

104. For discussion of needs in this context see A. Hasman, T. Hope, and L. Østerdal, "Health Care Need: Three Interpretations" (2006) 33 *Journal of Applied Philosophy* 145.

In the debates surrounding the correct formula, much attention has understandably focused on Quality Adjusted Life Years (QALY).¹⁰⁵ This is probably the most popular way of analysing the cost-effectiveness of treatments and is widely used in decision-making when rationing healthcare. QALY, as used in rationing decisions, requires an assessment of three factors:

- How many extra years of life will the treatment provide this patient?
- What will the quality of those extra years be?
- How expensive is the treatment?¹⁰⁶

A treatment that provides a year of perfect health scores as one; however, a year of less than perfect health will score less than one. Death is equivalent to zero. Under QALY, therefore, a treatment that provides a patient with an extra year of perfect health would be preferred to a treatment which provides a patient with an extra year, but a year of pain and low quality of life.¹⁰⁷ A treatment which offered a large number of QALYs for a small amount of money would be highly cost effective, while one that produced a low number of QALYs for a large amount of money would not be.¹⁰⁸ Someone required to ration health services can therefore examine a range of different services and consider how many QALYs for how much money is provided by particular treatments.¹⁰⁹ NICE indicates that if a treatment gives £20,000 per QALY it is likely to be approved, whereas if it is more than £30,000 there will need to be a strong justification before approval.¹¹⁰ There are many ways in which one could argue that QALYs are problematic. For the

105. See G.P. Smith II, *Distributive Justice and the New Medicine* (Edward Elgar, 2008), at 2-3; M. Adler, "QALYs and Policy Evaluation: A New Perspective" (2006) 6 *Yale Journal of Health Policy Law and Ethics* 1 at 1-3.

106. J. Herring, *Medical Law and Ethics* (Oxford University Press, 2008), at 70.

107. M. Adler, "QALYs and Policy Evaluation: A New Perspective" (2006) 6 *Yale Journal of Health Policy Law and Ethics* 1 at 1-2.

108. *Ibid.* at 2.

109. National Institute for Health and Clinical Excellence, *The Guidance Manual* (NICE, 2007), para 8.1.3; National Institute for Health and Clinical Excellence, *Social Value Judgements*, (NICE, 2005) para 4.2.

110. National Institute for Health and Clinical Excellence, *Social Value Judgements*, (NICE, 2005) para 4.2.

current purposes my complaint will be with the way they are too often used in a way which ignores the significance of caregivers.

QALY is normally used in a highly individualistic fashion, focusing just on the impact of the treatment on the particular patient. The improvement in the patient's quality of life alone is considered and the impact on the caregivers counts for nothing. Imagine, for example, a drug which prevents incontinence. It may be with a highly incapacitated patient receiving excellent care that the benefit of the drug will be very limited.¹¹¹ It might therefore score very low indeed on a QALY scale. The fact that the drug might have a dramatic impact on the quality of life for the caregiver would not be relevant under a traditional analysis of QALY, unless it can be shown that the impact on the caregiver is such as to affect the quality of care and thereby harm the patient.

Calculations based on QALYs usually do not include an assessment of behavioural symptoms.¹¹² If the treatment does not impact the health of the individual, even though it might alter his or her behaviour, it does not count as a benefit for the purposes of a QALY calculation. However, behavioural symptoms, can have a huge impact on the quality of life of a caregiver.

Even if the interests of caregivers are examined, they may be found to count for nothing. In 2006 NICE considered whether to approve a drug which could delay the impact of Alzheimer's Disease. They considered whether to take into account the benefit of the treatment to caregivers, but concluded:

The Committee considered that although at any point in time a carer may have a higher utility if they were caring for a person responding to drug treatment than if the person were not on the drug or not responding to the drug, the effect of the drug would be to delay progression of the condition, in which case the carer would still be faced at some time in the future with the same difficulties caused by disease progression. Exceptions could be if the person did not progress to later and more difficult stages of the disease within 5 years or because of death.¹¹³

This argument is, with respect, unconvincing. The claim appears to be that if someone is going to have the burden of caring for a relative suffering from

111. See J. Herring, "The Place of Carers" in M. Freeman (ed.), *Law and Bioethics* (OUP, 2008) for a discussion of this issue as it applied to the decision of NICE to limit access to drugs to treat Alzheimer's disease.

112. *Ibid.* para 4.2.6.

113. National Institute for Health and Clinical Excellence, *Donepezil, Galantamine, Rivastigmine (Review) and Memantine for the Treatment of Alzheimer's Disease (Appraisal Consultation)* (NICE, 2006), para 4.3.10.2.

Alzheimer's Disease at some point in their life then it matters not whether that is now or at some future point in time. Accordingly, medication which simply delays the inevitable onset of Alzheimer's Disease does not benefit the caregiver. However, delaying the onset of the condition provides the benefit of the caregiver having a longer time with his or her loved one before the condition takes its toll. Maybe in purely financial terms the loss to the caregiver is no different, but in terms of quality of life there is certainly a loss.

The failure to consider the interests of caregivers when making rationing decisions means that the costs to national health systems or insurance companies' budgets are given weight, but the costs to caregivers count for nothing. Yet the costs to the individual caregiver are costs to real people whose lives bear the blight of caring. By contrast, any cost to the State or insurance companies is spread widely. Politically, of course, the approach is understandable. Costs to the government are in the public eye and impact the sensitive issue of levels of taxation. Costs to caregivers go unnoticed in the public arena, although they are real enough to those who suffer them, and real enough in their effect on society as a whole.

It must not be thought, however, that including the costs to caregivers when making rationing decisions is without difficulty. There are dangers that it will mean that those cared for by a large number of caregivers or a more vulnerable caregiver will be regarded as having a greater call on health care resources than a person who is alone, with no family or caregivers.¹¹⁴ In *Rogers*,¹¹⁵ the English Court of Appeal approved the use of social and personal characteristics for determining which patients should be given Herceptin¹¹⁶ under the National Health Service if it was not possible to fund the treatment of all those who needed the drug. The court held that it could be appropriate to "make the difficult choice to fund treatment for a woman with, say, a disabled child and not for a woman in different personal circumstances."¹¹⁷

114. Although see D. Shickle, "Public Preference for Health Care" (1997) *Bioethics* 277 for some evidence that surveys of the general public suggest that the number of dependants should be a factor in rationing healthcare. Contrast P. Anand and A. Wailoo, "Utility versus Rights to Publicly Provided Rights: Augments and Evidence from Health Care Rationing" (2000) 67 *Economica* 543.

115. *R (Rogers) v Swindon Primary Care Trust* [2006] EWCA Civ 392.

116. A drug for use in treatment of cancer.

117. *Ibid.* at para. 77.

Jo Bridgeman has rejected such an approach.¹¹⁸ She argued:

The needs of a child with disabilities are no different whether they are met by her mother or another. The needs of a woman with breast cancer are no different, whether she is the carer of a child with disabilities or not.¹¹⁹

In some ways this is a surprising comment in light of her comments in the same article which reflect many of the views expressed in this article,¹²⁰ namely that we should not view patients in isolation, but in the context of a network of dependencies. The problem with saying, “[t]he needs of a woman with breast cancer are no different, whether she is the caregiver of a child with disabilities or not,” is that it imagines we can assess the needs of patients without looking at the network of relationships in which they find themselves.

However, this may be to misinterpret Bridgeman’s point. Her argument is that we all live in a network of dependencies. So all women with breast cancer have people who are dependant on them and we should not be in the job of giving greater preference to some dependant relationships over others. Indeed, there is a danger that the woman’s own identity becomes subsumed within a ‘caring role.’ As Bridgeman noted it is interesting that the PCT in *Rogers* regarded as an exceptional case for treatment for breast cancer, “caring for a disabled child,” rather than, say, outstanding success in a career, or other criterion.¹²¹

There is, as Bridgeman argued, something unpleasant about seeking to compare “the worth of the lives of women centred around their caring responsibilities.”¹²² However, if there is to be rationing of health care resources there must be some way of ranking the needs of patients. The choice is between either ignoring the network of those in caring relations, or comparing them. Whilst sharing Bridgeman’s distaste, if we must ration

118. J. Bridgeman, “‘Exceptional’ Women, Healthcare Consumers and the Inevitability of Caring” (2007) 15 *Feminist Legal Studies* 235.

119. *Ibid.* at 243.

120. We would agree that a society seeking to promote an ethic of care would ensure that such essential drugs are available.

121. J. Bridgeman, “ ‘Exceptional’ Women, Healthcare Consumers and the Inevitability of Caring” (2007) 15 *Feminist Legal Studies* 235, at 243.

122. *Ibid.* at 244.

medical resources I would rather make the comparison than ignore the relationship patients are in.¹²³

So, we have seen in this discussion that the primary method of allocating health care resources, the QALY approach, fails to appropriately take into account the interests of caregivers. In the allocation of health resources, it has been argued, the benefits to those caring for and being cared for by the patient should be taken into account, as well as the benefits to the patient themselves. Indeed it has been argued that there is no way of separating the benefits to the patient and those they are in caring relationships with. It has, however, been acknowledged this is not straight-forward. There is a lack of research into the benefits on caregivers of particular medication and in particular a lack of a theoretical model of giving appropriate weight to those benefits when rationing decisions are made. Further, there are the difficulties inherent in seeking to compare different sets of caring relationships. Despite these difficulties, it is argued that rationing decisions should not be restricted to considering the benefit to individual patients, without recognition being given to the network of relationships within which they live.

6. CAREGIVERS AND THOSE LACKING CAPACITY

The second area I wish to examine concerns the treatment of people who lack mental capacity. Medical decisions are made on behalf of those who lack mental capacity based on what is perceived to be in their best interests.¹²⁴ The *parens patriae* jurisdiction in Anglo-American jurisprudence protects those who lack mental capacity from harming themselves.¹²⁵

Medical lawyers are familiar with the dispute between those who support a best interests test and those who support a substituted judgment test.¹²⁶

123. This discussion opens the debate over whether an alternative to consequentialist QALY approach is preferable. See, e.g., J. Harris, "Justice and Equal Opportunities in Health Care" (1999) 13 *Bioethics* 392; George P. Smith II, *Distributive Justice and the New Medicine* (Edward Elgar, 2008).

124. Although quite what "best interests" means in this context is hotly debated.

125. N. Cantor, *Making Medical Decisions for the Profoundly Disabled* (MIT Press, 2005).

126. B. Rich, "Medical Paternalism v. Respect for Patient Autonomy: The More Things Change the More They Remain the Same" (2006) 10 *Michigan State University Journal of Medicine and Law* 87.

Under the “best interests” approach,¹²⁷ the decision-maker decides what is in the best interests of the person lacking capacity. Under the substituted judgement approach,¹²⁸ decisions are made based on an assessment of what the person would have decided if he or she currently had capacity.¹²⁹ These two approaches are commonly presented as competing approaches and fierce debate has surrounded which is preferable.¹³⁰

In fact, the two approaches are more similar than might at first appear.¹³¹ In the Mental Capacity Act of 2005, English law firmly nailed its colours to the “best interests” mast. However, the Act explains that in determining a person’s best interests, consideration should be taken of “the person’s past and present wishes and feelings” and “the beliefs and values that would be likely to influence his decision if he had capacity.”¹³² A similar approach can be found in American courts in applying the best interests test.¹³³ So, the decision that the person would have taken can carry some weight in determining what is in his or her interests.¹³⁴ Under the substituted

127. *In re Grady*, 426 A.2d 467, 481-83 (N.J. 1981); see also *In re K.I.*, 735 A.2d 448, 450 (D.C. 1999); *In re L.W.*, 482 N.W.2d 60, 70 (Wis. 1992).

128. *In re L.H.R.*, 321 S.E.2d 716, 721-23 (Ga. 1984); *In re Conservatorship of Torres*, 357 N.W.2d 332, 341 (Minn. 1984); *In re Guardianship of Ingram*, 689 P.2d 1363, 1372 (Wash. 1984).

129. Most courts restrict the application of substitute judgment to cases where the individual was once competent and, therefore, evidence can be found as to the person’s subjective preferences. See *In re K.I.*, 735 A.2d 448, 455 (D.C. 1999).

130. A. Buchanan, “The Limits of Proxy Decisionmaking for Incompetents” (1981) 29 *UCLA Law Review* 386; R. Dresser “Missing Persons: Legal Perceptions of Incompetent Patients” (1994) 46 *Rutgers Law Review* 609.

131. N. Cantor, *Making Medical Decisions for the Profoundly Mentally Disabled* (MIT Press, 2005), at 105; E. Miller, “Listening To The Disabled: End-Of-Life Medical Decision Making and the Never Competent” (2006) 74 *Fordham Law Review* 2889.

132. Mental Capacity Act 2005, § 4(6).

133. See further N. Cantor, “Discarding Substituted Judgment and Best Interests: Toward a Constructive Preference Standard for Dying, Previously Competent Patients Without Advance Instructions” (1996) 48 *Rutgers Law Review* 1193.

134. For a recent English judicial acknowledgement that a best interests test will not necessarily match the patients wishes see *R (Burke) v. General Medical Council* [2005] EWCA 1003.

judgment approach, a decision-maker would ask themselves what decision the individual would make if the individual had capacity.¹³⁵ Of course, under the substituted judgment approach, best interests may play an important role. Decision-makers should require some convincing that a person, if competent, would choose to do something that would harm them. As this shows, the differences between a best interests and substituted judgement approach are less than may initially be supposed. Indeed, quite a number of commentators have recommended a mid-way position between the two.¹³⁶

The purpose of this article is not to consider whether or not the best interests approach is preferable to the substituted judgement approach.¹³⁷ The question I want to focus on is, under either of these approaches, what weight is to be attached to the interests of caregivers.

At first sight the interests of caregivers are simply not relevant to a best interests assessment. The English law is governed by the Mental Capacity Act 2005. Section 4 provides some requirements for a person, or court, seeking to ascertain what is in a person's best interests. Of particular note, for the present purposes, is section 4(7):

He must take into account, if it is practical and appropriate to consult them, the views of – ...

(b) anyone engaged in caring for the person or interested in his welfare...as to what would be in the person's best interests...¹³⁸

While it is welcome to see a statutory acceptance of the relevance of the views of caregivers as to what should happen to those they care for, it is important to realise the limited nature of this. Most significantly, the caregiver can only speak as to what would be in the incapacitated person's welfare. Caregivers views as to what would assist them are not a relevant consideration, unless they can be 'dressed' up as being about the benefit of

135. J. Robertson, "Organ Donations by Incompetents and the Substituted Judgment Doctrine" (1976) 76 *Columbia Law Review* 48.

136. E.g., S. Halliday and L. Witteck, "Decision-Making at the End-of-Life and the Incompetent Patient: A Comparative Approach" (2003) 22 *Medicine and Law* 533.

137. See also N. Cantor, "Discarding Substituted Judgment and Best Interests: Toward a Constructive Preference Standard for Dying, Previously Competent Patients Without Advance Instructions" (1996) 48 *Rutgers Law Review* 1193; J. Arras, "The Severely Demented, Minimally Functional Patient: An Ethical Analysis" (1988) 36 *Journal of American Geriatrics Society* 938.

138. Mental Capacity Act 2005, § 4(7).

the individual. So, if the caregiver can say, “if my views on this issue are not listened to I will cease to care for the individual and hence it is in their best interests that my views are accorded weight,” then her views can be taken into account.¹³⁹

A good example of this narrow understanding of best interests is found in the Mental Capacity Act’s Code of Practice:

Pedro, a young man with a severe learning disability, lives in a care home. He has dental problems which cause him a lot of pain, but refuses to open his mouth for his teeth to be cleaned.

The staff suggest that it would be a good idea to give Pedro an occasional general anaesthetic so that a dentist can clean his teeth and fill any cavities. His mother is worried about the effects of an anaesthetic, but she hates to see him distressed and suggests instead that he should be given strong painkillers when needed.

While the views of Pedro’s mother and carers are important in working out what course of action would be in his best interests, the decision must *not* be based on what would be less stressful for them. Instead, it must focus on Pedro’s best interests.¹⁴⁰

Despite this apparently clear approach, I will argue that the best interests approach can be interpreted in a way which includes the interests of caregivers.

First, under a best interests approach one can take account of the views and opinions of the person concerned. This is accepted under section 4(6) of the English Mental Capacity Act 2005 which requires the decision maker, when deciding what is in the best interests of the individual, to consider:

- (a) the person’s past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity)
- (b) the beliefs and values that would be likely to influence his decisions if he had capacity, and
- (c) the other factors that he would be likely to consider if where able to do so.¹⁴¹

139. For an example of this kind of reasoning, see *Hart v. Brown*, 289 A.2d. 386, Conn. (1972); *In re Y (Mental Patient: Bone Marrow Donation)* [1997] 2 WLR 556 (FD). I have discussed the latter case further in J. Herring, “The Welfare Principle and the Rights of Parents” in A. Bainham, S. Day Sclater, and M. Richards (eds), *What is a Parent?* (Hart, 1999).

140. Department of Constitutional Affairs, *Mental Capacity Act 2005: Code of Practice* (DCA, 2007), para. 5.7.

141. Mental Capacity Act 2005, § 4(6).

In American law, too, there appears to be a general acceptance that the incompetent person's values while they were competent can be taken into account when assessing his or her current best interests, at least insofar as doing so will not harm him or her. *In re Boyd*¹⁴² held that following the incompetent patient's deeply felt religious preferences was the "only way to pay full respect to the individuality and dignity" of the patient. It may be that some are not convinced that a best interests approach should place any weight on the values of a person lacking capacity. But consider the English case of *Ahsan v. University Hospitals Leicester NHS Trust*.¹⁴³ There, a Muslim woman lacked capacity following a very serious injury. In the context of tort litigation the issue arose whether she should be cared for in accordance with her religious beliefs when doing so would be more costly than standard care. The argument was made that because she did not know what was happening, it was of no benefit to be treated in accordance with her beliefs. The judge forcefully rejected the argument and held that it was in her best interests to be treated in accordance with her religious beliefs, even though she was unaware of what was happening to her.¹⁴⁴ I suggest that few would disagree with that conclusion.

In Ronald Dworkin's influential discussion regarding making decisions for incompetent people he drew a much discussed distinction between experiential interests and critical interests.¹⁴⁵ Critical interests are those things which make a person an individual; the things that make a person's life worthwhile. Experiential interests may produce pleasure and fun (e.g. doodling) but are not part of a person's life goals.¹⁴⁶ If this distinction is used, I would argue that for many people their relationship with their caregiver, especially where it has been with someone whom they have a close relationship, will be part of their critical interest. Their partnership, marriage, sibling relationship, or friendship will have been a defining part of their lives. The individual's interest in promoting that relationship as give and take will be a part of their critical interest which should continue after losing capacity.

If it is correct that a person's prior values can be considered, then I suggest there are very few people indeed who would want decisions about them when incapacitated to be made entirely based on their own best

142. *In re Boyd*, 403 A.2d 744, 750 (D.C. 1979).

143. *Ahsan v. University Hospitals Leicester NHS Trust* [2006] EWHC 2624.

144. *Ibid*, at para 56.

145. R. Dworkin, *Life's Dominion* (Alfred A. Knopf, Inc., 1993), at 224.

146. *Ibid*.

interests with no consideration being given to the person caring for them, especially where that is a loved one. At the very least, surely there are few people who want a decision to be made which causes enormous harm to their caregiver because it procures for them the most marginal of gains. And surely not where a choice can be made to prefer an option which benefits them, and hugely helps the caregiver; over an alternative which would benefit them slightly more, but hugely harm the caregiver. As the Massachusetts Supreme Court held, “[a]n individual who is part of a closely knit family would doubtless take into account the impact his acceptance or refusal of treatment would likely have on his family.”¹⁴⁷

It should be recalled that “best interests” is not an entirely materialistic concept.¹⁴⁸ As Butler-Sloss, P. in *JS v An NHS Trust* stated, the court should define best interests “in the widest possible way.”¹⁴⁹ The Mental Capacity Act Code of Practice states:

The Act allows actions that benefit other people, as long as they are in the best interests of the person who lacks capacity to make the decision. For example, having considered all the circumstances of the particular case, a decision might be made to take a blood sample from a person who lacks capacity to consent, to check for a genetic link to cancer within the family, because this might benefit someone else in the family. But it might still be in the best interests of the person who lacks capacity. ‘Best interests’ goes beyond the person’s medical interests.¹⁵⁰

It seems, then, that a consideration of best interests can take into account the obligations towards others that a person properly has.¹⁵¹ Would you say it would be in your best interests to be waited on hand and foot by an army of slaves, meeting your every need? Would we want our friends to be undertaking enormous sacrifices to achieve relatively minor gains for us?

147. *Guardianship of Roe*, 421 N.E.2d 40, 58 (Mass. 1981); see also *In re Ingram*, 689 P.2d 1363, 1370 (Wash. 1984).

148. See, e.g., *In re John Doe*, 481 N.Y.S.2d 932 (N.Y. 1984) (holding that “the benefits to the incompetent if his brother lives outweigh the physiological and psychological risks” of a bone marrow transplant).

149. [2002] EWHC 2734 (Fam.), para 60.

150. Department of Constitutional Affairs, *Mental Capacity Act 2005. Code of Practice* (DCA, 2007), para 5.48.

151. Dan W. Brock, “What is the Moral Authority of Family Members to Act as Surrogates for Incompetent Patients?” (1996) 74 *Milbank Quarterly* 599.

Would anyone find such a way of life rewarding or beneficial?¹⁵² We should impose the answers to these questions on those who are incompetent.¹⁵³ Indeed, both American and English law recognise that people lacking capacity can be treated in a way which does not directly benefit them, because both countries permit an incompetent person to be involved in research.¹⁵⁴

Third, I argue that it is not possible to consider the incompetent person's best interests without considering the well-being of his or her caregivers.¹⁵⁵ The interests of the two are intertwined. No caregiver could possibly undertake the task of caring if every decision which has to be made is solely on the basis of what is in the interests of the cared for person. As the President's Council on Bioethics put it:

As a simple rule of thumb, caregivers should do the best they can do; they are never compelled to do what they cannot do, but they are obligated to see how much they can do without deforming or destroying their entire lives. But in practice, this rule of thumb rarely leads to any fixed rules, because every person faces different demands and has different capacities. And inevitably, we cannot do our best simultaneously in every area of our life: that is to say, we cannot do our best for everyone all the time; we cannot be there for everyone all the time; we cannot devote resources to everyone equally all the time.

To be a caregiver is to confront not only the limitations of the person with dementia who relies upon us entirely, but our own

152. J. Piliavin and H-W. Charng, "Altruism: A Review of Recent Literature and Research" (1990) 16 *Annual Review of Sociology* 27 discusses recent evidence that altruism does exist in human nature.

153. See the case law on donations of body parts from minors; e.g., *Curran v. Bosze*, 566 N.E.2d 1319, 1320. See also the helpful discussion of the case law in N. Herbert, "Creating a Life to Save a Life: An Issue Inadequately Addressed by the Current Legal Framework Under Which Minors Are Permitted to Donate Tissue and Organs" (2008) 17 *Southern California Interdisciplinary Law Journal* 377.

154. Mental Capacity Act 2005 § 30. The American law is well summarised in N. Cantor, *Making Medical Decisions for the Profoundly Mentally Disabled* (MIT Press, 2005), chapter 5.

155. See R. Veatch, *The Patient-Physician Relation Part 2* (Indiana University Press, 1991), at 229.

limitations as human beings who are more than just caregivers or who are caregivers in multiple ways for multiple people.¹⁵⁶

The relationship of caring does, and should, involve give and take. It would not be in the interests of a cared-for person to be in a relationship which was utterly oppressive to their caregiver. What *is* in the cared-for person's interests is to be in a relationship with her caregiver which promotes the interests and well-being of them both.¹⁵⁷ It is, therefore, argued that when considering the best interests of an incompetent person such an assessment must consider her well-being in the context of her relationships. This might involve making decisions which in a narrow way do not explicitly promote the incompetent person's welfare or even slightly harm it, if that is a fair aspect of a caring relationship which is a necessary part of the incompetent person's well-being.

So, can we be more precise about how the interests of caregivers should be taken into account? I argue that the key is to examine the decision at issue in the context of the relationship between two people. How does this decision fit in with the giving and taking involved in this relationship that has taken place in the past and will take place in the future? This will mean that caregivers will not be treated "as objects to be manipulated as part of patient care."¹⁵⁸ The relationship between caregivers and dependants must not be one-sided. Of course, it is extremely difficult, if not impossible, to imagine that a decision that severely harms either the caregiver or the dependant could be seen as justified in the context of a relationship.

It may help to add what I am not saying.¹⁵⁹ I am not claiming that treating a person lacking capacity in a way which is not in their best interests, but promotes altruism, creates a moral good.¹⁶⁰ Altruism which is forced is

156. President's Council on Bioethics, *Taking Care* (President's Council on Bioethics, 2005), at 198.

157. For a development of this approach in relation to parents and children see J. Herring, "The Human Rights Act and the Welfare Principle in Family Law – Conflicting or Complementary?" (1999) 11 *Child and Family Law Quarterly* 223. See also L. Jansen, "Child Organ Donation, Family Autonomy, and Intimate Attachments" (2004) 13 *Cambridge Quarterly of Healthcare Ethics* 133.

158. M. Minow, "Who's the Patient?" (1994) 53 *Maryland Law Review* 1173, at 1191.

159. See P. Lewis, "Procedures that are Against the Medical Interests of Incompetent Adults" (2002) 22 *Oxford Journal of Legal Studies* 575.

160. See J. Lantos, "Children as Organ Donors: An Argument for Involuntary Altruism" in G. Burgio and J. Lantos (eds), *Primum Non Nocere* (Elsevier, 1994).

probably not properly described as altruism. At least it does not exhibit the characteristics which we admire in altruism.¹⁶¹ Nor am I saying that the procedure is justified because making decisions which benefit the caregiver can be shown to create benefits for the dependant person in the long run.¹⁶² My claim also differs therefore from John Hardwig who regards it as a matter of justice when families make sacrifices for an incapacitated patient.¹⁶³ His approach fails to place sufficient weight on the intermingling of the interests of the incapacitated person and his or her caregivers.

Rather my claim is that the incompetent person cannot be viewed in isolation. He or she must be viewed in the context of the relationships which he or she is in. This will be a fair and just assessment which promotes the rights and interests of both parties. As with all healthy relationships, the caregiving relationship will involve give and take. Under the orthodox analysis there will be some decisions which are in the interests of the person lacking capacity and some which are in the interests of the caregiver. This is how it is in real life in a well-working caring relationship and this is how it should be in the law.

7. AUTONOMY AND CAREGIVERS

I have just discussed how the interests of caregivers should be taken into account when the patient has lost capacity; but what about when the patient has capacity? For those who possess legal capacity, the cardinal principle is the right of self-determination or autonomy.¹⁶⁴ Subject to the constraints of the law, people remain generally free to live their lives as they wish. In the context of medical law this is reflected in the right to bodily integrity - the right for our bodies not to be touched or interfered without our consent.¹⁶⁵ As Justice Cardozo famously declared:

161. See J. Seglow, "Altruism and Freedom" (2002) 5 *Critical Review of International Social and Political Philosophy* 145.

162. M. Goodwin, "My Sister's Keeper?: Law, Children, And Compelled Donation" (2007) 29 *Western New England Law Review* 357.

163. J. Hardwig, "The Problem of Proxies with Interests of Their Own: Toward a Better Theory of Proxy Decisions" (1993) 4 *Journal of Clinical Ethics* 20.

164. D. Beylveland and R. Brownsword, *Consent in the Law* (Hart, 2007), at 1-35.

165. The right to bodily integrity is an essential component of the right to liberty protected by the Fourteenth Amendment of the Constitution of the United States. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 279 (1990); *Union Pac. RR. Co. v. Botsford*, 141 U.S. 250, 251 (1891).

Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent, commits an assault¹⁶⁶

As indicated at the start of this article, a consideration of caring relationships challenges the pre-eminence which is given to the principle of autonomy. As Pamela Scheininger put it:

Because the law is conceived of in its application to the isolated individual rather than in its application to the individual's various associations and relationships, the law does not accurately reflect the reality of human existence. The legitimacy of the law is thus challenged. Individual persons do not operate as independent, separate entities, but as interdependent, connected parts of larger groups. In failing to deal with laws as they affect human relationships, lawmakers ignore a fundamental aspect of our humanity¹⁶⁷

A recognition of the significance of caregiving relationships which are central to all our lives shifts the starting point away from the autonomous individual to a person sited in interdependent relationships. As Susan Dobbs explained:

My emphasis is on the ways in which human vulnerability and dependency have come to be viewed as evidence of a failing to attain or retain autonomous agency, rather than as conditions for agency and autonomy among humans. I argue that the dominant social understandings of what it is to be a citizen, autonomous agent or person contribute to the exploitation and disadvantage of care workers. I argue that a better approach to the social and ethical issues raised by paid care requires a refocussing on inherent human vulnerability. On my view, it is only through this refocussing that the material, emotional and social supports that make selfhood and citizenship possible can be adequately understood. . . . Attention to *vulnerability*, by contrast, changes citizens' ethical relations from those of independent actors carving out realms of right against each other and the state, to those of mutually-dependent and vulnerably-

166. *Schloendorff v. Society of N.Y. Hosp.*, 105 N.E. 92, 93 (N.Y. 1914).

167. P. Scheininger "Legal Separateness, Private Connectedness: An Impediment To Gender Equality In The Family" (1998) 31 *Columbia Journal of Law and Social Problems* 283.

exposed beings whose capacities to develop as subjects are directly and indirectly mediated by the conditions around them.¹⁶⁸

Once, then, we accept our inherent vulnerability and dependency on others, the image of the all-powerful rights bearer falls away. So seen, autonomy is not so much about rational choice but, rather, it is relational. Far then from needing what Justice Brandeis identified as the “right to be let alone,”¹⁶⁹ we need our relationships recognised and protected. Linda Barclay noted that “our ongoing success as an autonomous agent is affected by our ability to share our ideas, our aspirations, and our beliefs in conversation with others. It is unlikely that any vision or aspiration is sustained in isolation from others.”¹⁷⁰

Our sense of self is a mixture of interlocking and sometimes conflicting social identities.¹⁷¹ For many people, their self-definition is based on relationship, be it as a mother, a Muslim or a Minnesota Vikings fan. We are not in reality free to live our lives as we choose because we are constrained by the responsibilities, realities and relationships which embed our lives.¹⁷² Hence, Allan Johnson has called our culture’s insistence that we are separate and autonomous as patriarchy’s “Great Lie.”¹⁷³ As Eva Feder Kittay wrote:

I propose that being a person means having the capacity to be in certain relationships with other persons, to sustain contact with other persons, to shape one’s own world and the world of others, and to have a life that another person can conceive of as an imaginative possibility for him- or herself. . . . We do not become a person without the engagement of other persons—their care, as well as their recognition of the uniqueness and the connectedness of our human

168. S. Dodds, “Depending On Care: Recognition of Vulnerability and the Social Contribution of Care Provision” (2007) 21 *Bioethics* 500, at 501.

169. *Olmstead v. United States*, 277 U.S. 438, 478 (1928) (Brandeis, J., dissenting).

170. L. Barclay, “Autonomy and the Social Self” in C. Mackenzie and N. Stoljar (eds.), *Relational Autonomy* (Oxford University Press, 2000), at 57.

171. See A. Donchin, “Understanding Autonomy Relationally” (2001) 26 *Journal of Medicine and Philosophy* 365.

172. J. Nedelsky, “Reconceiving Autonomy: Sources, Thoughts and Possibilities” (1989) 1 *Yale Journal of Law and Feminism* 7.

173. A. Johnson, *The Gender Knot* (Temple University Press, 1997), at 30.

agency, and the distinctiveness of our particularly human relations to others and of the world we fashion.¹⁷⁴

This then challenges the very notion that there are medical decisions which are “mine,” in the sense of just affecting me. Indeed as I have argued elsewhere, even to say “my body is mine” is to over-simplify the issue:

First, our bodies are often in a state of dependency on other bodies. Second, our bodies are constantly interacting and reacting with the world around us. Third, our bodies are not immutable entities, but are constantly changing and recreating themselves. We need to move away from a vision of a society of bodies which are only of concern to ourselves and recognise that to a significant degree, our bodies depend on other bodies and the world around us for their meaning and survival.¹⁷⁵

We need then to accept that decisions about medical treatment are not just the patients’ decisions.

Does this mean, then, that a patient can automatically have treatment imposed against her wishes, because that is what those she is in relationships with think is best? No, because relational autonomy recognises the responsibilities that go with relationships. Selma Sevenhuijsen has contrasted an approach based on ethics of care with one based on traditional legal approaches: “the ethics of care involves different moral concepts: responsibilities and relationships rather than rules and rights.”¹⁷⁶ The responsibilities arising from a relationship are therefore central to an ethic of care. What these require and what they entail, however cannot be set down in stone. Every relationship is different and hence the responsibilities created differ too.¹⁷⁷

So understood, the responsibilities arising from the relationship affect both the patient and with whom she is interdependent.¹⁷⁸ It would only be in

174. E. Feder Kittay, “When Caring is Just and Justice is Caring: Justice and Mental Retardation” in E. Kittay and E. Feder (eds), *The Subject of Care: Feminist Perspectives on Dependency* (Rowman & Littlefield, 2002), at 266 (internal citation omitted).

175. See J. Herring and P.-L. Chau, “My Body, Your Body, Our Bodies” (2007) 15 *Medical Law Review* 34, at 51-2.

176. S. Sevenhuijsen, *Citizenship and the Ethics of Care* (Routledge, 1998), at 107.

177. K. Bartlett, “Re-Expressing Parenthood” (1988) 98 *Yale Law Journal* 293, at 299.

178. J. Bridgeman, *Parental Responsibility, Young Children and Healthcare Law* (Cambridge University Press, 2007).

an extreme case where compelling surgery would be a fair aspect of the relationship or that demanding it would be in accordance with the responsibilities the relationship creates. An approach based on an ethic of care would encourage a dialogue between the patients and those around them to determine what ought to be done. It would recognise that the decision needs to be made in the context of the interdependent relationships between all those involved.

8. CONCLUSION

This article has considered the position of caregivers in medical law and ethics. It should not be forgotten that far more medical care is provided to people by caregivers than is provided by medical professionals. Indeed it might not be putting it too strongly to say that caregivers play a more important role in medical well-being than the professionals do. Certainly that is true on a day-to-day level for most people. Yet the care provided by caregivers is largely ignored in medical law and ethics. They are invisible in the textbooks and most of the academic writings.¹⁷⁹

This article has argued that we cannot consider the interests of the patient in isolation from those who are in caring relationships with them. However proudly the law may seek to trumpet our autonomy, our self-sufficiency and our rights, that is a false picture of our lives. We are not almighty, but vulnerable; not all-knowing rational people in control of our lives, but ignorant, vulnerable and subject to the responsibilities, ties and joys of our relations with others; not independent and self-sufficient, but dependent on others in countless ways.

179. J. Herring, "Where are the Carers in Healthcare Law and Ethics?" (2007) 27 *Legal Studies* 51.